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AUTHOR Peckens, Gloria
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ABSTRACT

A brief history of care for handicapped individuals on Guam is traced from early refusal to acknowledge their existence, to their increased visibility and current efforts toward least restrictive placement for education and care. It is explained that societal attitudes toward the handicapped in Guam are characterized by pity, neglect and repulsion which result in hiding them either in the home or in large residential institutions. Three conclusions are drawn: 1) the community must be ready for changes to occur; 2) the attitudinal change can be quickened by intensive public education efforts; and 3) transition to the least restrictive delivery of services will occur only when and to the degree that the general population is ready. (CL)

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The History of Care for the Low-Incident Handicapped in the Territory of Guam: Is there a Necessary Development Change in the Delivery of Special Education Services?

by Gloria Peckens

Assistant Professor of Special Education

College of Education

University of Guam

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The History of Care for the Low-Incident Handicapped in the Territory of Guam; Is there a Necessary Development Change in the Delivery of Special Education Services?

(Presented at Special Education In Transition, An International Symposium on Special Education, Taiwan, January 23-28, 1978, by Gloria Peckens, Assistant Professor of Special Education, College of Education, University of Guam.)

Only one-half of the title for this paper appears on your program. It is actually the second half upon which I wish to focus attention. In addition, after submitting the abstract to the committee for this symposium, I was privileged to secure additional information through personal communication with individuals in the Guam departments of public health, social services and education and also in the community. As a result I have revised the paper and title to some degree.

A better title than appears on your abstract might be Is There a Necessary Attitude - Developmental Evolution for the Acceptance of Special Education Services? Guam: An Example. It is upon this question the paper will focus attention.

We have all grown up with educators extolling the value of studying history - ancient history, world history, local history - not just to know and appreciate our past, our heritage, BUT to learn from it. We are taught we can learn to avoid errors of societies and systems that went wrong and to refrain from activity history shows us has not, in the final analysis, been totally successful and in many cases disasterous.

After a half-century of living and twenty-five years of teaching in many places, I find difficulty in accepting that rationale for the study of history. Societies do NOT seem to learn from the past; rather, it seems necessary for each community or nation to go through these stages of development even though others through their development illustrate different, new examples. It matters not whether we are talking about government, or social services, or social attitudes.

Man seems to have been fighting wars for the same reasons down through the centuries. Man's concern for his fellow man seems to go through the same patterns until he is ultimately ready to accept responsibility for the care and education for all people in that society. These are but two examples. One could list more.

I suspect the term "recapitulation" might be appropriate; but I hesitate to use it, as it is often used by certain researchers in our field in reference to neurological development. G. Stanley Wells had a similar theory of child development. This paper, however is dealing with societal attitudes which seem to show developmental stages toward acceptance and tolerance.

The origin of this notion of the necessity of an attitudinal evolution to enable acceptance of newer modes of service for the handicapped goes back to the late 60s, when it was my privilege to live in Dacca, East Pakistan, with my husband who was Associated with the Institute for Education and Research at the University of Dacca through a United States Agency for International Development contract. During those two years we also had the opportunity to travel widely throughout the provinces representing the United States information services. This provided me with an opportunity for observation and gathering information otherwise difficult to acquire.

Perhaps the basis for the beginning thoughts on this concept of the necessity of societal attitude development or evolution is best initially communicate by example. USAID funds were used to build a beautiful, modern educational facility on the edge of the campus of the University of Dacca. In this building was housed a model demonstration school (U.S. concept) at the elementary level staffed by U.S. educated Pakistanis. Competition for admission to this school was fierce, thus obviously the student body was made up of Pakistani children whose parents occupied high socio-economic levels. It was in this "demonstration school" that the U.S. funded Institute for Education and Research educated future Pakistani teachers for the nation's village schools.

On land in front of this distinctly U.S. model-school was a typical city elementary school housing 200 students in a two room building of bamboo and thatch with its only furniture long rows of crude benches. It was staffed by teachers who were fortunate indeed to have even finished elementary school themselves. Their salaries and occupational status in their country were lower than those of servants employed by Pakistani and foreign families. Obviously, our educational training did not prepare the Pakistani teacher for the real world.

In the rural provinces of East Pakistan, USAID had numerous projects and men working to help the village farmers use newer methods and tools for agriculture to provide more food for a nation with serious problems of famine. These newer methods and tools were felt to be more efficient and if followed would bring more income for the farmer. But the US tractors and irrigation pumps sat idle - often broken down. We had forgotten to teach the people how to maintain them, thus the people were using tools and methods that one could trace back to before the advent of christ. This is understandable, perhaps you are thinking. We had failed to teach in a proper sequence the skills necessary; but there was another little example related to this project to improve agriculture and thus the life of man.

Our agricultural experts did succeed in helping the farmer in growing larger potatoes; but when they tried to convince the farmer to save the largest potatoes of that first crop, to be used as seed to ensure a second crop of even larger potatoes, the farmers refused, thinking the experts were foolish like all experts who tried to tell them how to do things. They sold the beautiful, large potatoes and keep only the smallest, poorest potatoes for the seed for the next crop. Obviously, that next crop produced the small, poor quality potato of the past.

During this two year stay in Pakistan, I was asked to present a paper for a seminar sponsored by the East Pakistan Federation of the Blind. Of the six main speakers, two of us were U.S. citizens and three others were educated in the United States. My colleagues in their papers were calling for various types of expensive care and integrated services for the blind in the public school system. This was at a time when children were maimed to make them more likely to receive alms when begging. This was at a time when only 10% of the six year old East Pakistani normal children entered the first grade and only 10% of that group went on into the second grade. With these mental images to set the stage, I will move on to a more orderly development of this paper.

The history of care for the handicapped on Guam is intended to, in part, illustrate this idea of the need for societal readiness or attitudinal evolution before innovative delivery service systems can be successfully adopted.

Care for the handicapped on Guam, in its early history, was provided by the family, which followed an "extended family" system. Care of handicapped individual was the responsibility of the family, with care for the individual passing from parents to sibblings or other relatives as long as the handicapped individual lived. It was expected of the family and there was no alternative.

Following World War II services slowly began with the mildly intellectually handicapped child being identified in the elementary school after a history of academic failure and upon the teacher's demand for the removal of these "slow-learning, troublesome" students. Slowly self-contained special education classes at the elementary level were opened, taking all students who presented problems to teachers. The process was quickened when federal funds became more readily available.

It was upon parent demand and initiative that a facility was established as a private venture to provide training for the moderately handicapped, primarily in the area of intellectual deficit. This was a day-care training facility. This service in 1960 became a part of the government's financial and administrative responsibility. To this day, it does not accept students who are not toilet-trained, or who do not have at least a minimal social/group adjustment. Services for these individuals have not been steady and currently are federally funded field-projects.

Slowly, in the last 10 to 15 years minimal educational services have been extended to the secondary level. During these years the Vocational Rehabilitation Workshop has been serving two groups, the more traditional group needing re-training because of injury or health problems and the handicapped individual in a sheltered workshop environment.

The ability of those in the sheltered workshop, when speaking of the clients as a group, would more likely, if in the continental US, be in community or industrial training and/or jobs with only the more severely handicapped in the workshop. There is a start in this direction, but business and our light industry have been slow to understand or accept the potential of these handicapped individuals.

It was-again-parents who in the late 60's sought aid for their children with auditory and visual impairments. The service for these children began in a temporary building and has now reached the stage where some have been mainstreamed in regular classrooms (a limited number), where they learn with their normal peers through the assistance of interpretors. The more severely or multi-handicapped are served by the day-care facility mentioned earlier.

There is currently an effort to mainstream the mildly handicapped with varying degrees of success. Many teachers refer to these students as "my special education students", others are very open in their determination to have these "slow students" removed, and a very few are trying to truly individualize and help all students.

The care on Guam varies little in its growth and development from that of the US. The mildly handicapped were identified by teachers demanding separate services for them. The more severely handicapped received services through the demand of a small group of determined parents which forced the government to provide services, usually funded by federal project grants.

There is one major difference. Guam has no residential care facility. A small number - around 14-who could not or cannot be cared for in the home (and were found) have been sent to the state facility in Hawaii financed by the Government of Guam. By and large the more severely and profoundly handicapped are still hidden and cared for by the family.

When one speaks of the history of care for a particular group, there is also a need to define this group and present statistical data in reference to prevalence. There are numerous definitions and prevalence fiqures for the United States as you all know. Equally well known is the fact that all such surveys, studies, and statistical data tables caution us to regard these numbers as estimates or approximations.

When turning attention to prevalence and definitions on Guam such cautions are doubly important. As soon as one social service agency publishes the results of their survey, another agency supplies a set of their own. Public, social, and educational agencies are forced to make long range plans on limited, unstable data. Guam is not unique in this area. In any country where data is to be gathered in a relatively newly-defined area, this problem must be faced. Because of these problems this paper will not attempt to supply tables and figures of prevalence rates.

In reference to the term "low-incidence," again it is necessary to consider the geographic area about which one is speaking. In 1970, the United States Bureau of Education for the Handicapped, when speaking of their prevalence data and rank-order of handicapped conditions as of July 1, 1968, used both the words "estimate" and "approximately" in one sentence alone. Statistical information was being gathered on Guam at the same time--1968--for the development of a comprehensive, controversial, and contested data to date: however I will use the two sets of data since they were based upon surveys of the same year, 1968, and do provide some basis for determining which may be low-incidence handicapping conditions for the Unites States and Guam.

In rank-order from high to low-incidence in the U.S., the list of handicapping conditions was:

Speech Impaired
Emotionally Disturbed
Mentally Retarded
Learning Disabled
Hard of Hearing
Deaf
Crippled or other Health Impairments (combined)
Visually Impaired
Multi-Handicapped

In the 1968 Guam survey of 51,092 people, the high disability incidence groups are listed in rank-order as:

Heart Conditions
Orthopedic Conditions
Mentally Slow
Diabetic
Asthma
Arthritis
Neuro-Motor
Epilepsy
Blind
Deaf

Remember the listings for Guam is considered to be the high incidence group and also note the terminology and categories are quite different, with certain categories omitted entirely. If one were to regroup the Guam list combining heart, asthmatics, diabetic, etc., conditions and refer to them as health impairments, this term would be overwhelmingly at the top of the high-incidence list, whereas in the United States the combined crippled and health impairment group is listed as seventh out a group of nine.

It would appear from this data that there are few emotional/social disorders and that the prevalence of mental retardation is lower than found to be the case in the United States. The final survey report indicated that the data reporting mental illness was thought to be somewhat low due "to the stigma attached to admission that there is a person with this type of disability in the family". The surveyors reported "locked closets and rooms, confinement to an area by rope or chain, or 'exile' to a special little shed in the rear of the lot". Additionally, the designation "mentally retarded" was felt to be too controversial, thus the term "mentally slow" was used. Again the report speaks of the stigma attached to admission that someone in the family "just isn't quite right" which led them to believe that the "mentally slow" were not being identified, but that they were present and services were needed. It would appear then from the data gathered and from the statements of the researchers that it was far easier for families to provide data concerning health or physical problems than it was to discuss or admit that a member of the family was mentally ill or mentally retarded.

There is another important fact to which attention must be drawn. In 1964 there was an epidemic of rubella of dreadful size. There were 459 cases reported as compared to 27 cases in 1963 and 61 cases in 1965. As children with handicapping conditions were identified, it was learned that a statistically significant number of their mothers had indeed contacted rubella during the first trimester of that pregnancy. The incidence of hearing, visual, and sometimes accompanying mental impairment is higher on Guam than is typical for the U.S. This is in part attributed to the rubella epidemic of 1964.

This information concerning incidence of handicapping conditions on Guam illustrates how careful one must be in using prevalence figures from elsewhere to determine local needs and care services.

Very briefly, let me recall for you the general history of care for individuals with physical, mental, or emotional handicaps. Three stages in the development of attitudes toward the handicapped child are often listed. We are all familiar with the tragic persecution, neglect and/or death inflicted upon those who were handicapped. From this stage mankind developed a sense of pity and thus provided them protection, and from that stage has come in varying degrees to acceptance and integration of the handicapped into society.

Most areas of the world have in varying degrees passed from stage one, except perhaps in the most primitive societies in very isolated areas. It is my contention that we are in stages two or there depending upon the attitudinal development or evolution of the community about which one might be speaking. It is, further, my contention that one cannot successfully impose "innovative" types of care, services or education for the handicapped until the community or societal-attitudes have reached that developmental stage. In the second stage of development, society felt pity and guilt and also replusion. The solution to this problem was to build residential institutions to shelter and hide the handicapped. Those families who did not place their child in an institution, in most instances, kept them hidden within the confines of the immediate family.

Guam is caught in between these last two stages. The older population is firm in its Catholic faith, have large families and believe it is God's will or punishment if a handicapped child is born. If you believe it is God's punishment, obviously you would not wish your neighbor to know of this. During the past several weeks, I have contacted the two social workers for the homebound severely handicapped who have reported to me several recent documented cases of hidden handicapped individuals, one of whom was kept in a cage. Such cases are reported less frequently now, but this reaction to or result of a societal-attitude does still exist.

Like Special Education, Guam too is "in transition." The younger population are limiting family size, are seeking higher levels of education and are beginning to openly accept the handicapped individuals.

I well recall a Stateside consultant in Special Education who worked with us in 1968. He proposed mainstreaming handicapped children at that time. Remember that was in 1968 when the survey I have mentioned found the population very reluctant to admit to having mentally ill or retarded family members. Crippling

conditions were also hidden. The arguement of this consultant was that Guam should learn from the mistakes or history of the United States and thus pass over - eliminate - several stages of care development. He would have had us abolish the self-contained special education classrooms, move the moderately handicapped into workshop situations. This consultant and many others since him have left our island frustrated and wondering why we could not "see the light."

Guam has tried experimentally, with small groups, innovative systems of care, treatment or education when funded by federal sources; however, when the Federal support is exhausted the service is seldom funded locally. The general population appears just not ready for the acceptance or tolerance of the handicapped such programs required.

Now in 1978, Guam is trying to quickly implement the Federal Law which calls for the least restrictive education for all individuals. I described--to a Guamanian student and former teacher aid--my class for trainable mentally retarded individuals which was housed in a regular elementary school in the U.S. in 1958. Her immediate reaction was that the local parents of the normal school students would "never allow it...would be frightened" and convinced that their children would not be safe. Our regualr classroom teachers are not trained for this and are in general frustrated in their teaching efforts. Many instances of the teachers' inability to accept the handicapped child in their regular classroom certainly must lead to speculation about the attitudes of parents. Mainstreaming under these conditions is not the least restricitive environment.

In summation then may I say:

1) The community must be ready--At the necessary developmental stage--for changes to take place.

2) This attitudinal evoluation can be quickened by intensive efforts at public education.

3) Transition to "the least restrictive" delivery of services will happen, but only when and to the degree the general population is ready.

John Gardener, a former United States Secretary of Health, Education, and Welfare described the work with the handicapped as "a series of great opportunities brilliantly disguised as unsoluble problems." We, too, must see the task ahead of us as a "great opportunity" but let no one tell us it is an "unsoluble problem." With determination, dedication and patience, attitudes can be changed; tolerance and acceptance can be achieved; and fuller, meaningful opportunities for the handicapped can be provided. But it is less likely to be successful if the population has not reached that stage of understanding or acceptance and toleration.